# Management of epilepsy

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The child first and always

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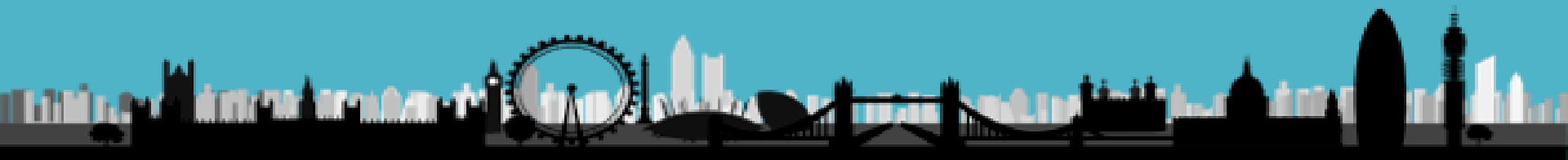


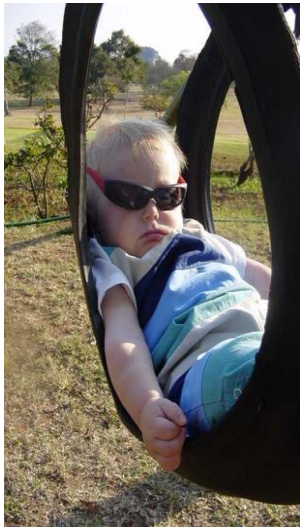
# objectives

- Demonstrate a basic understanding of the ‘Epilepsies ‘, associated co-morbidities and the impact this may present within the education environment
- Acknowledge the importance of an agreed comprehensive health care plan for children and young people with epilepsy
- Recognise other non-pharmacological treatments for epilepsy when traditional medications fail to work

# What is epilepsy

- The incidence of epilepsy in children in developed world ranges from 3.2/5.5/1000( Camfield, 2015)
- Epilepsy- disease of the brain, 2 unprovoked sz occurring within a 24 hour timeframe or one unprovoked seizure with probability of further sz or the diagnosis of a epilepsy syndrome(ILAE, 2014)
- Causes may include genetic, trauma , metabolic or structural
- Its not one condition but may be better understood as 'the epilepsies'
- May lend to co-morbidities
- Treatment aim is seizure freedom!

# What does epilepsy mean for the children we care for ?




slide courtesy of Matthew aged 13ye

# Diagnosis

A good history needed!!!!

When did it happen?

Was there any triggers?

How did the child and young person present?

How were they after the event?

Has it occurred before?

Birth history and development

Are they currently well?

Fit ,faint, cardiac ??

EEG/MRI

# Seizure presentation- ILAE 2017

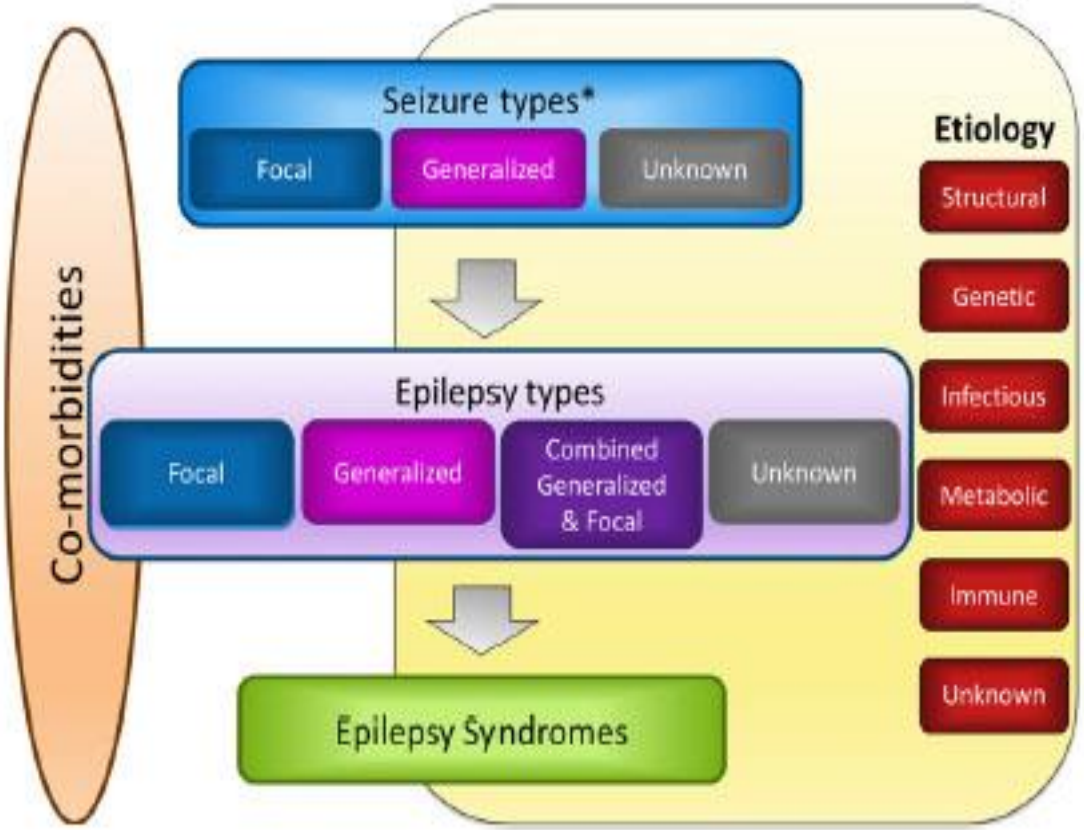
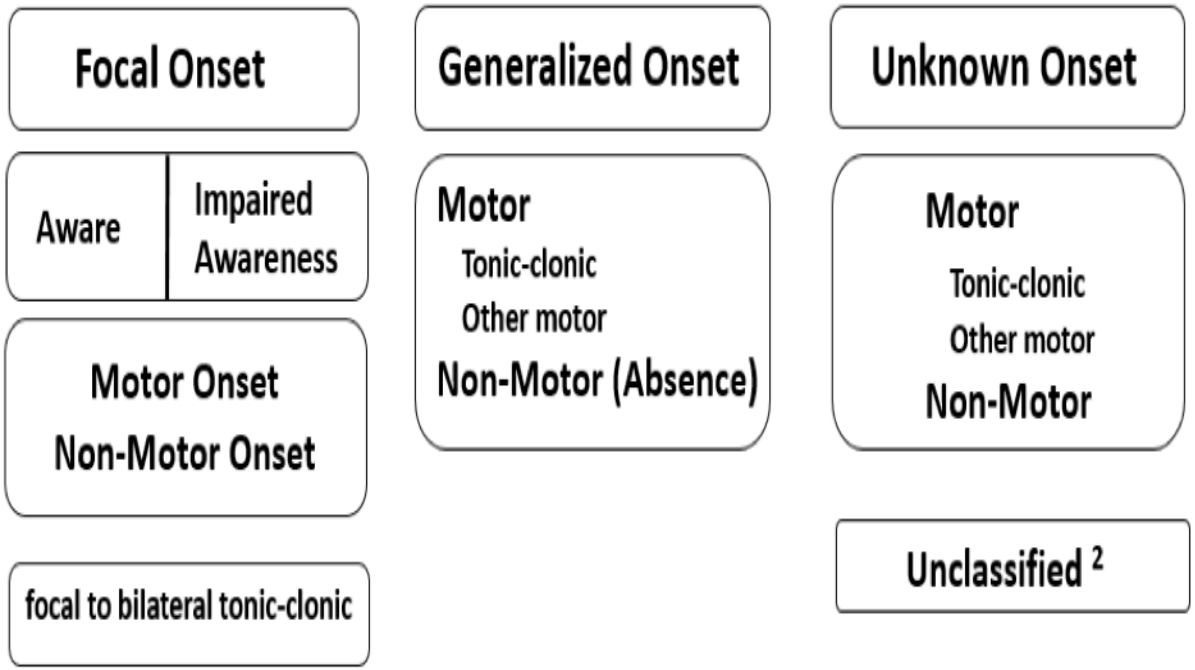



**Figure 1.**
Framework for classification of the epilepsies. *Denotes onset of seizure.
*Epilepsia* © ILAE

# ILAE 2017 Classification of Seizure Types Basic Version [1]




[1] Definitions, other seizure types and descriptors are listed in the accompanying paper & glossary of terms

[2] Due to inadequate information or inability to place in other categories

**Frontal Lobe:**

- Moving your head or eyes to one side
- Not being aware of your surroundings or having difficulty speaking
- Screaming, swearing or laughing
- Unusual body movements.

**Parietal Lobe:**

- Difficulty understanding words, language or difficulty reading
- Feeling that a part of your body is missing or doesn't belong to you.
- Sexual sensations
- , tingling, heat, pressure.

**Temporal Lobe:**

- Feeling frightened
- Deja-vu
- A strange taste or smell
- Rising sensation in the stomach
- Automatic behaviours such as lip smacking, repeated swallowing, chewing or more complex tasks such as dressing.

**Occipital Lobe:** Feeling of numbness

- Seeing things that are not there
- A change in vision or loosing vision
- Nystagmus
- Eye pain

# Medication choices

100 years ago phenobarbital was introduced

Now have approx. 27 Anti-epileptic medications(AED) to choose from

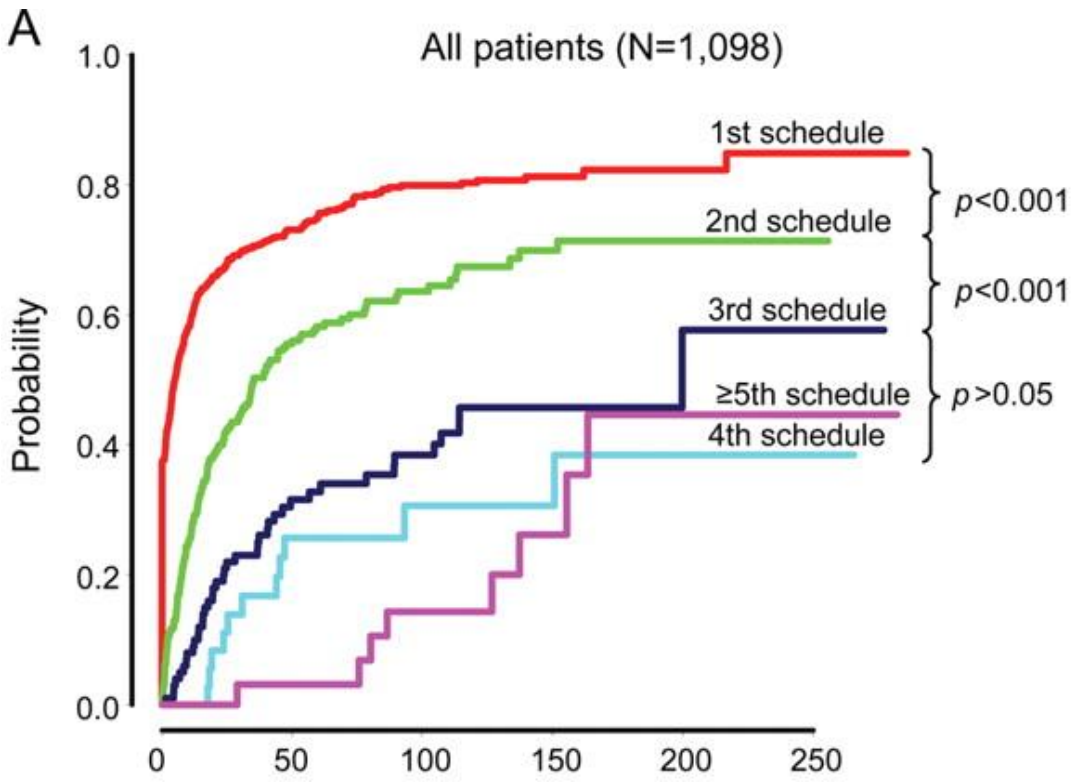
But does this mean seizure freedom?

First choice of AED may lead to 70% seizure freedom may reduce to 5% on reaching third +medication

Breakthrough seizures and potential side effects

# Cumulative probability of being seizure-free by time from start of treatment and number of antiepileptic drug regimens

**Brodie M et al. Neurology 2012;78:1548-1554**



# Common syndromes

## Childhood Absence Epilepsy

Onset aged 4-8yr

Sz presentation absences

Diagnosis provided on EEG, hyperventilation may induce events

Treatment – sodium valproate /ethosuximide

Usually benign- 70% controlled on medication, 10% may develop further sz in adolescent

Impacts on education/safety

# Juvenile Absence Epilepsy

Onset age 9 years to teenage years

Sz presentation- absences and atypical absences

8 in 10 children will also have GTCS

Diagnosis made on history , EEG , hyperventilation

Treatment includes sodium valproate, lamotrigine

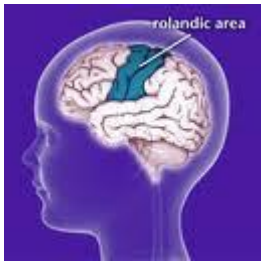
Minimal impact on learning if well controlled

Ethosuximide may increase GTCS

1 in 10 will be photosensitive

Will usually be a life long epilepsy

# Benign Rolandic Epilepsy




‘centro-temporal’

Onset 3-10 years

Focal seizures-tingling to the tongue and cheek, speech slurred , will still be responsive – can progress to GTCS

Benign , usually grow out of it in teenage years

We may not treat with medication but provide a rescue medication only

Impact on education -10-15% will have speech and language difficulties

# Juvenile Myoclonic Epilepsy

Onset age 12-16 years

Sz presentation, myoclonic jerks, absences and GTCS

Photosensitive

Diagnosis –history and typical EEG

Treatment –sodium valproate, lamotrigine and levetiracetam

Life long epilepsy

Impacts on daily living

# Non Epileptic Seizures

More common than one may think

Triggers may be sleep deprivation, stress or emotions

The young person is not usually aware that the event is ‘not’epileptic

NES can occur in conjunction with epileptic seizures

Diagnosis – are they not responding to appropriately trialled medications, video, video telemetry, how are they post seizure

# Co-morbidities

Most children will achieve seizure freedom with treatment and attend a mainstream school

However many are likely to experience co-morbidities

- Depression/anxiety
- Lower self esteem and confidence
- ADHD/ASD
- Learning and behavioural concerns

In the general population 10% would have a additional diagnosis of co-morbidity.

This may rise to 20-30% with a ‘un complicated epilepsy’

Refractory epilepsy , early onset may have 50-60% risk, specifically associated with their neurological condition

Rutter 1970/Davies et al 2003

# Risk factors

Negative impacts may result from uncertain prognosis, unpredictability of seizures but also:

Younger seizure onset age

Structural brain abnormality

New onset seizure disorder

Some AED and polytherapy

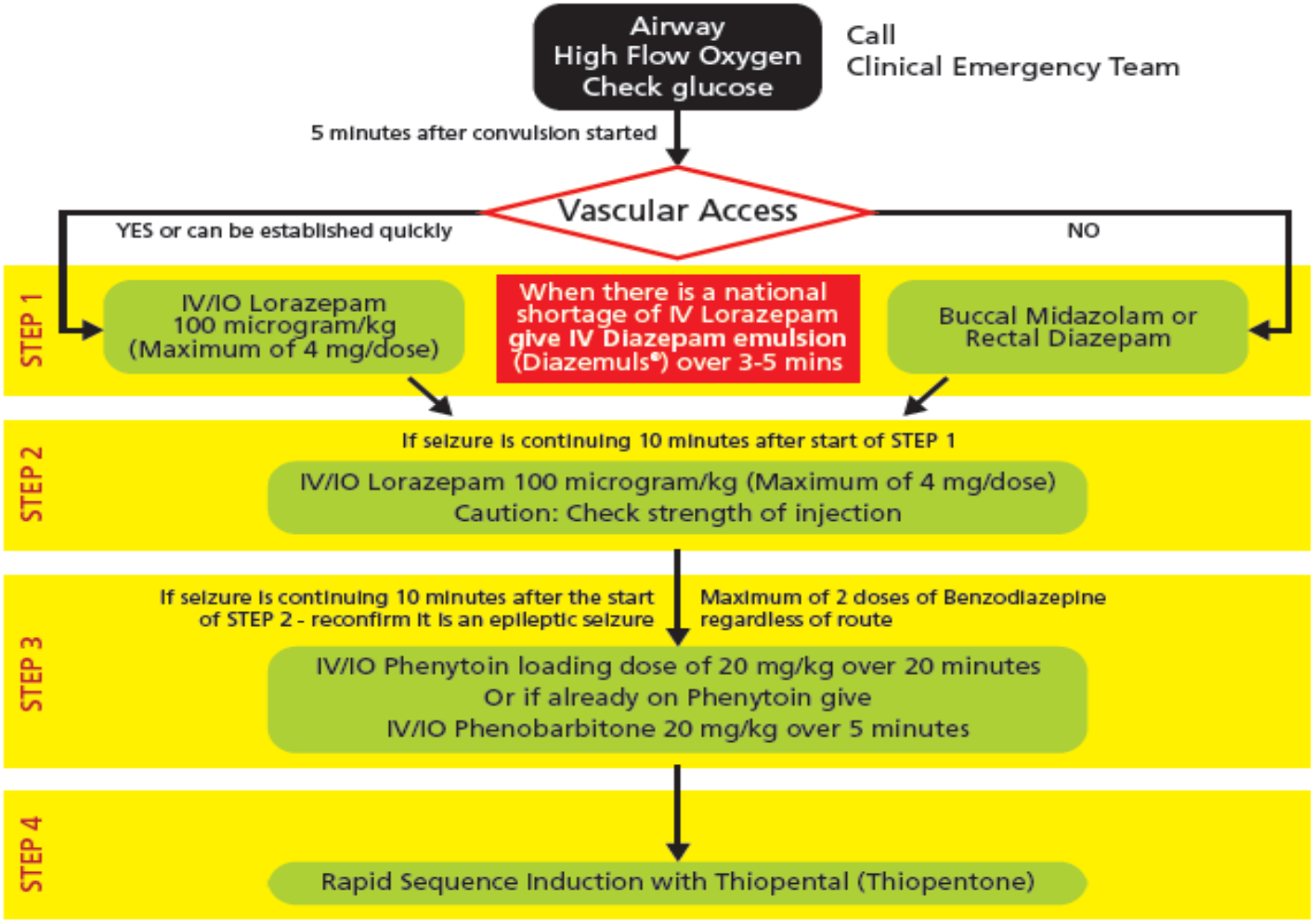
Family/psychosocial factors

Common treatable conditions include: ADHD , ODD, anxiety disorders and depression, support and simple self strategies can help!

# Status Epilepticus

- A generalised convulsion lasting 30 minutes or longer or when successive convulsions occur without a period of recovery in between (APLS 2011)
- Convulsive or non-convulsive status

# APLS guidance



# Rescue Medication

| Medication |
| --- |
| Buccal Midazolam |
| Diazepam |
| Lorazepam |
| Paraldehyde |

# EHCP careplan

What information should be included

Agreement between all parties

Should be comprehensive and inclusive

Epilepsy passport

Description of event

Safety, when to be concerned

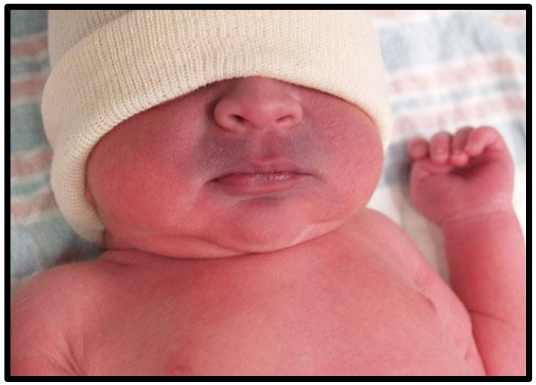
Rescue medication

Trained staff , parental contact

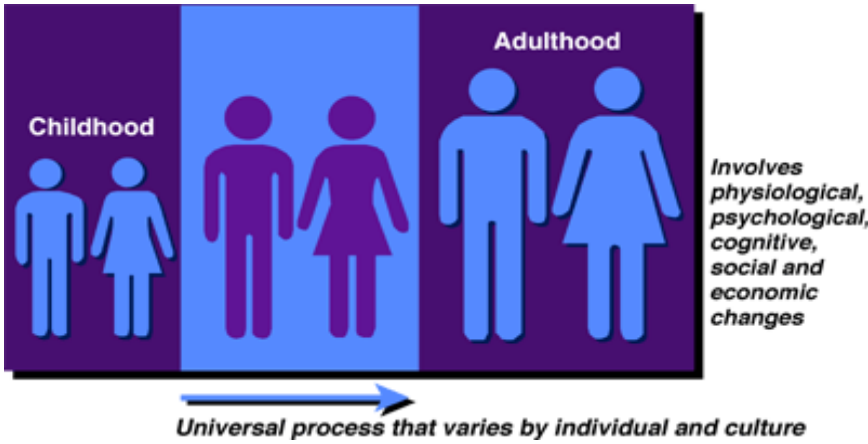
Local epilepsy networks

# Documentation of Seizures

- Which part of the body was affected first? left/right upper/lower limbs?
- Was more than one part of the body affected at one time?
- What kind of movements occurred?
- Did the movements change?
- Did the child have a warning / aura?
- Were there any eye movements?
- Was there any loss of consciousness?
- Was there any hyper-salivation?
- Was there any cyanosis?
- What interventions were required?
- Document the exact length of seizure.



# Adolescent




- Sodium valproate
- Driving
- Alcohol
- Safety advice: water, sleep, medication adherence, contraception
- Pregnancy
- Lets give them goals to achieve to enhance independence/self care skills
- TRANSITION!!!

# Refractory epilepsy

- Failure of adequate trials of 2 tolerated appropriately chosen and used AED ( monotherapy or in combination) to achieve seizure free
- 20% may be potential candidates for pre surgical evaluation

- NICE 2012 – refer to tertiary care

- Consider: Pre-surgical evaluation
  Ketogenic diet
  VNS therapy

# Epilepsy surgery

NICE 2012 guidance

Development of Children's Epilepsy Surgery Service

Pre-surgical evaluation

# Children's epilepsy surgery programme

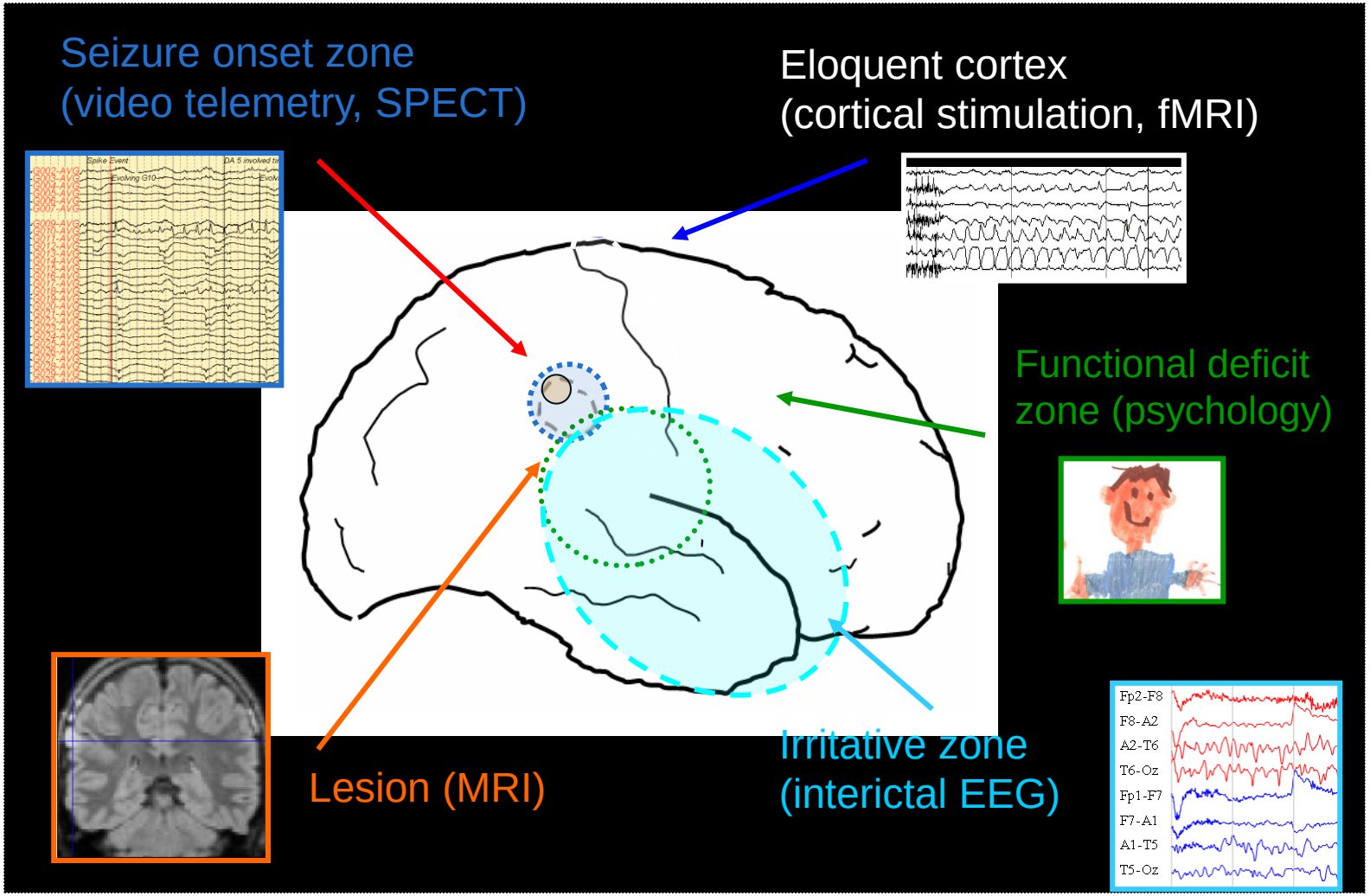
4 CESS centres across UK nationally commissioned expected to see a total of 1050 referral per yr with 350 surgical procedures (NHS England 2013)

GOSH has 4 designated telemetry beds and 60% of referrals are for pre surgical work up

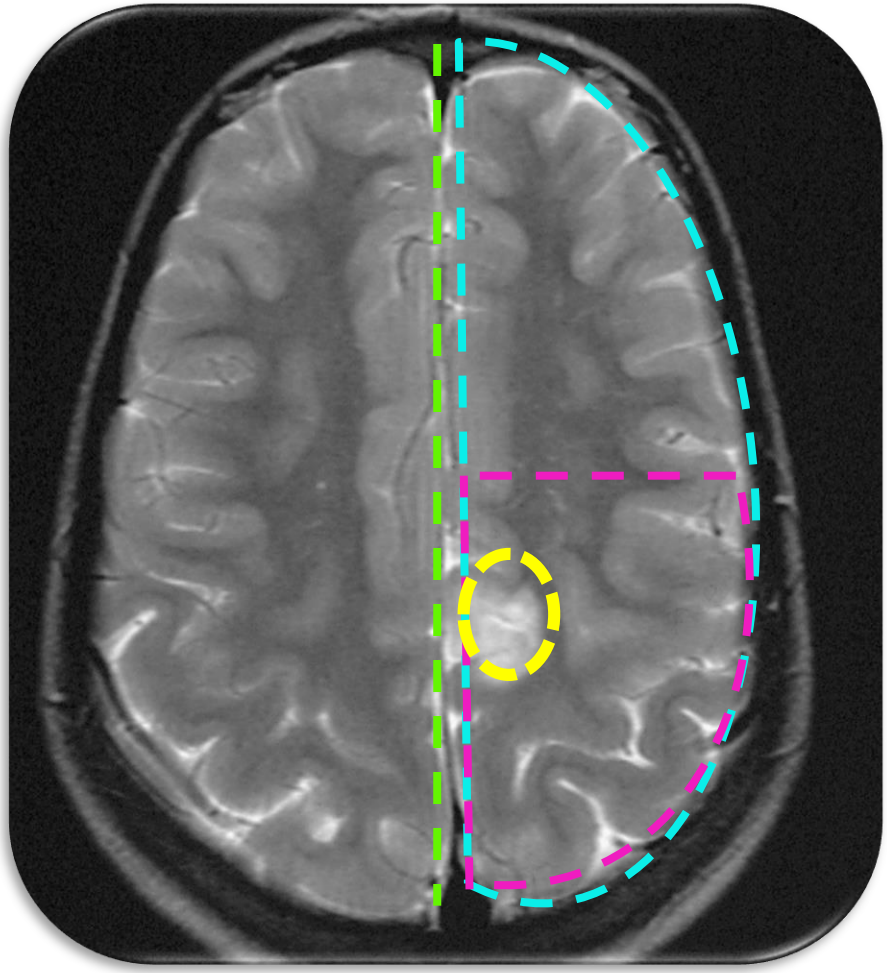
Monthly tele conference with other centres and we lead on under 6 years

We are now completing 100+ surgical cases a year inclusive of up to 24 SEEG/invasive monitoring

# Presurgical Evaluation

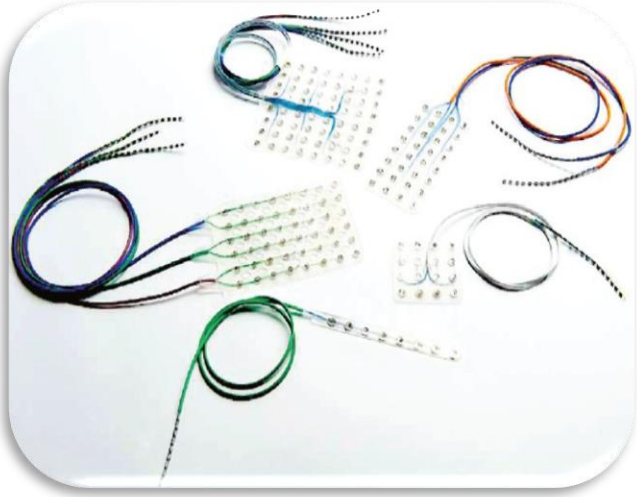


# surgical approaches



Lesionectomy
Lobectomy
Hemispherectomy
Corpus Callosotomy

Invasive EEG or stereo-EEG

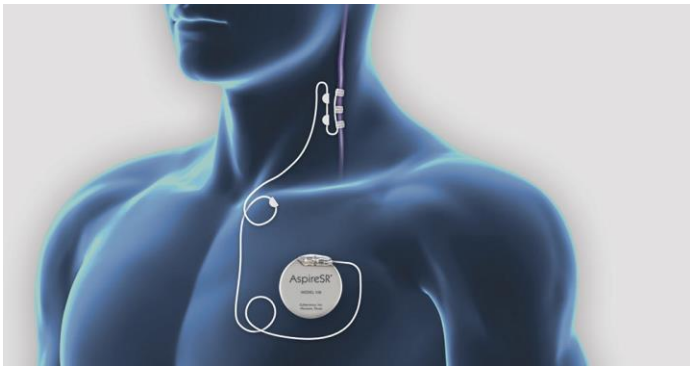


# Ketogenic Diet

- 1920's scientists noted starvation reduced seizures
- KD is high in fats, adequate in protein( for growth) and low in carbohydrates, provided by vegetables and fruit
- Diet mimics starvation , body produces ketones
- A diet of high fats, low carbs may reduce seizure for some children
- Growth and nutrition requires careful monitoring

# Vagus Nerve Stimulation Therapy

- Non-pharmacological therapy for epilepsy
- Repeated electrical stimulation of the left vagus nerve by the pulse generator device
- Benefits include- acute abortive- magnet
- Acute prophylactic
- Chronic progressive
- Other benefits?  Mood, behaviour, alertness, school
- How does it work?



# Case study 18yr female 1997

BH-term NVD no concerns, no relevant family history

Early development satisfactory

Febrile convulsion aged 3 not prolonged

Sz aged 7 , confused , stared, motor automatisms to hands slurred speech x2 per week may secondary generalise x2 a month

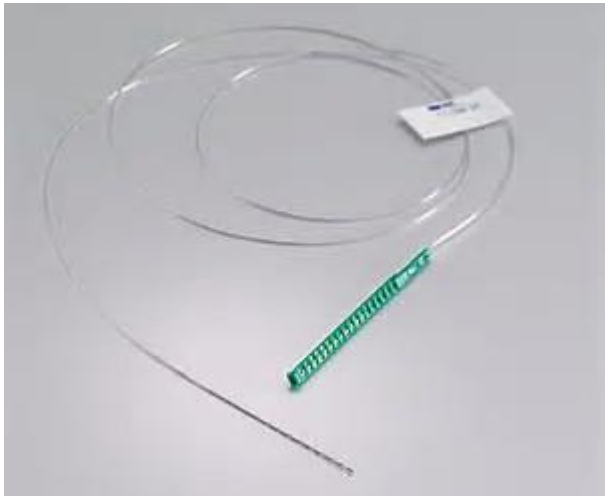
Review of MRI 2009 lesion –ve

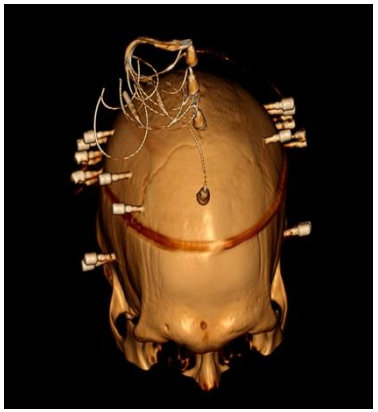
2014 telemetry admission, interictal, ictal semiology left temporal

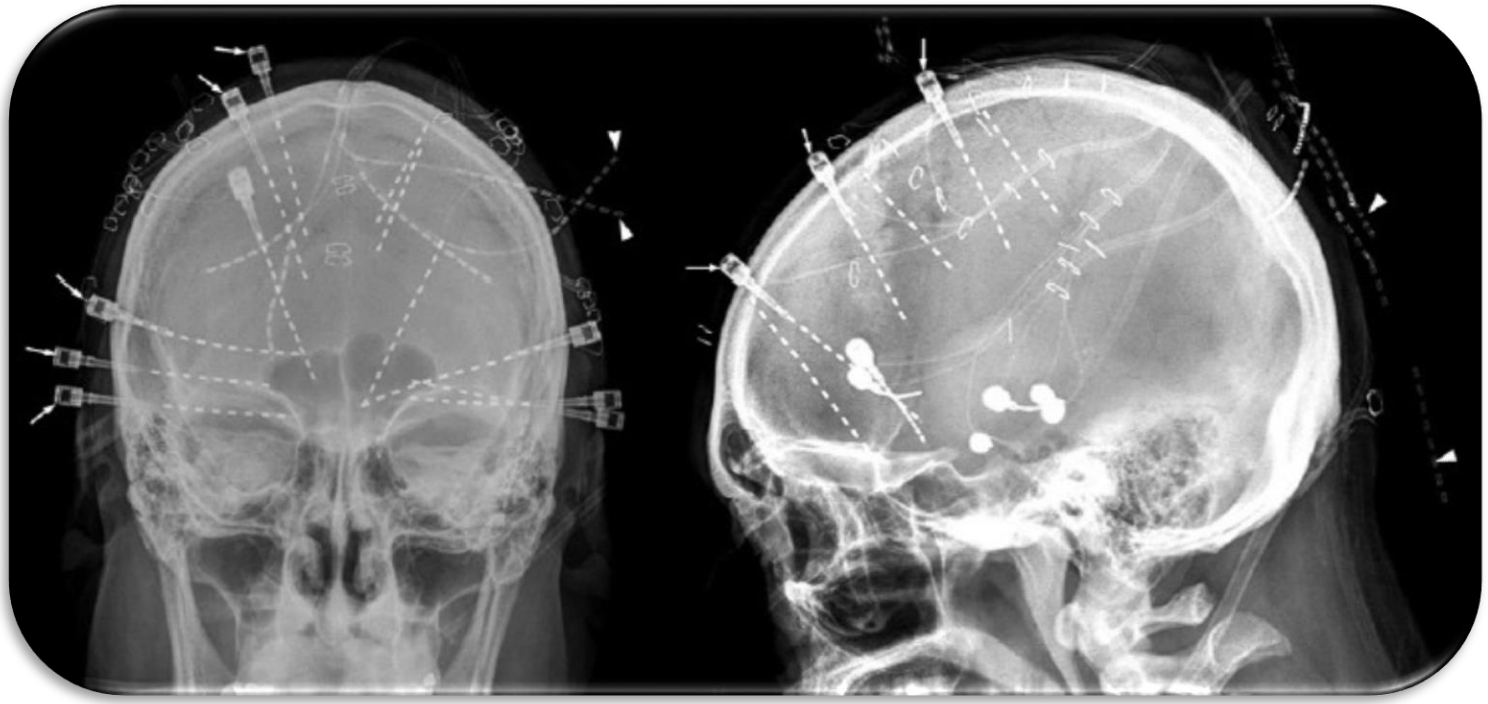
LFMRI left lateralised for language so SEEG 2015

Left anterior temporal lobectomy and amydalohippocampectomy Feb2016

Currently seizure free if medication taken, memory concerns and head aches







# CBD

- Cannabidiol ‘medical marijuana’
- 2007 GW Pharmaceuticals developed Epidiolex
- Double blind , randomised, placebo- controlled trial completed in Lennox-Gastaut syndrome and Dravets syndrome
- Trials have shown reduced frequency of convulsive seizures , Dravets showed 39% reduction
- Side effect profile includes somnolence, elevation of liver-enzyme activity, loss of appetite and diarrhoea(Devinsky,O. Cross, H. Laux,L et al ,2017)
- Long term effects?

# SUDEP

Sudden unexplained death in epilepsy

A child with epilepsy has 2-3 % increase risk of premature death- accident , drowning, suffocation and  SUDEP

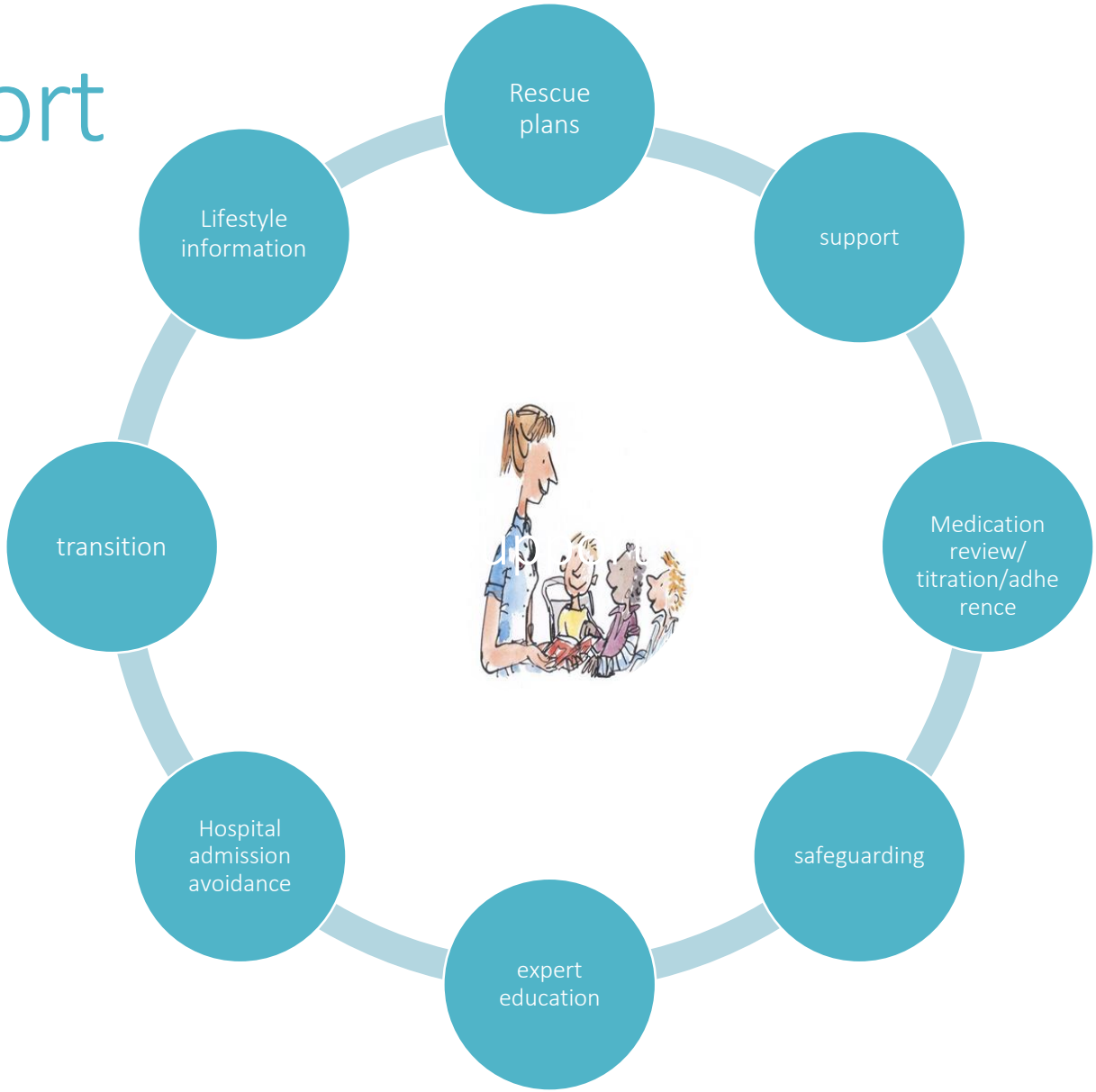
BPSU prospective study Oct 2016-Oct 2017 orange card notifications

Safety pillows – esuks

Seizure monitors

Reduce risk: medication adherence, good sleep pattern, alcohol/drug avoidance

# Support


Rescue plans
support
Medication review/ titration/adhe rence
safeguarding
expert education
Hospital admission avoidance
transition
Lifestyle information

# Summary

What does it mean for child in education:

EHCP

Full inclusion

charities

NICE

Epilepsy 12

# useful links

http://www.minded.org.uk/families - parenting tips to understand and support their

http://www.youngepilepsy.org.uk/

https://www.epilepsy.org.uk/

http://esuk.uk.com/ pillows

http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/epilepsy-passport/epilepsy-passport careplan

# Any questions please?

# With thanks

Clinical Nurse specialists Mark Heathfield, Emma Ninnis and Catherine O’Sullivan

My colleagues within the GOSH CESS programme